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'I'm not interested in research; i'm interested in services': How to better health and social services for transgender women living with and affected by HIV

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ABSTRACT

This paper presents results of a research priority setting process focused on trans women living with and affected by HIV across Canada. It features data from semi-structured interviews and focus groups conducted with a diverse group of 76 trans women in five urban centers across the country on how they have navigated health and social service programming within their geographic context. The results focus on the structure and types of services. Respondents offered simple, yet creative ways to address barriers to vital services based on their individual and collective experiences. Notably, participants stressed the need for 1) trans-friendly and trans-specific services, 2) integrated health services, and aid in navigating complex, overlapping systems, and 3) comprehensive community-based services. They also suggest employing trans women as care coordinators or case managers in order to foster more trans-friendly environments and empower community members. We identify concrete ways to improve health and social services at the level of service delivery and program design, as well as recommendations for future participatory research. We close with an interrogation of trans people, and trans women living with and affected by HIV in particular, as 'hard to reach' populations.

1. Introduction

1.1. Trans women and HIV service access

Transgender women have been disproportionately affected since the beginning of the HIV pandemic. More recently, transgender women have been formally recognized by the World Health Organization (2016) as a key population impacted by HIV, following a series of studies and systematic reviews documenting a high burden of HIV among transgender people globally (Baral et al., 2013; Herbst et al., 2008; Operario et al., 2008). For example, Baral et al. (2013) estimated that in 15 countries with available seroprevalence data at the time, the pooled HIV prevalence among transgender women was 19.1% and their odds of being infected with HIV were 49 times higher than the overall reproductive-age population. Research describing the hardships, challenges, and barriers trans women face when approaching and consuming HIV services is common (Bukowski et al., 2018; Dowshen et al., 2017; Eftekhar et al., 2020; Klein et al., 2020; Lacombe-Duncan et al., 2020; Maulsby et al., 2017; Munro et al., 2017; Sevelius et al., 2014). For example, an early study on transgender women of color sex workers in

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San Francisco identified structural barriers that trans women face in accessing vital HIV services, as well as health and social services (Nemoto et al., 2005). Nemoto and colleagues pointed to a lack of knowledge among healthcare and social service providers of trans women's specific healthcare needs, bias and stigmatizing attitudes among healthcare and social service providers, and the compounding stigma faced as both transgender women of color and sex workers. Rodríguez-Madera and Toro-Alfonso (2005) also identified gendered attitudes and structural barriers that trans women in Puerto Rico, 74% of whom worked in the sex industry, face when attempting to access HIV-related care.

The barriers that transgender women encounter in accessing HIV services have persisted over time and include discrimination and denial of care, lack of cultural competency among service providers, and anticipated violence and discrimination (Frank et al., 2019; Lyons et al., 2016; Reisner et al., 2017; Rood et al., 2016; Sevelius et al., 2016). These obstacles to accessing HIV care are echoed in multiple geographic contexts around the world (Costa et al., 2018; Eftekhar et al., 2020; Mitchell et al., 2019; Reisner et al., 2017; Rood et al., 2016; Samuel et al., 2018; Sevelius et al., 2016; Silva-Santisteban et al., 2016; Singh et al., 2014; Thompson et al., 2019). In a comprehensive review of the literature on trans women, HIV, and health and social services, Reback et al. (2015) identified a number of barriers to recruiting and retaining transgender women living with and affected by HIV into HIV-specific services. They claimed that outreach workers often encountered trans women who were uninterested in, suspicious of, or otherwise unable to follow up after an initial encounter and attempt at recruitment. They further suggested that offerings of nail polish, perfume, or other 'trans-women specific gifts' aided in building rapport with trans women who were suspicious of outreach workers who were not themselves trans, much less trans women. Poteat, Wirtz, and Reisner (2019) highlighted a number of interventions that could lead to both better participation in clinical HIV research, and to a reduction in the barriers transgender women face in gaining access to treatment and prevention services.

While there are multiple studies identifying the barriers trans women experience in accessing HIV services, we know less about the specific ways in which existing services could be improved to better align with the needs of transgender women living with and affected by HIV. Even less research has been done through primary data collection that explicitly asks transgender women to identify their priorities for change. Three studies point to the need for change including increased cultural competence, and the integration of HIV services with gender-affirming care. One study from Philadelphia included feedback from young transgender women on HIV treatment and prevention and called for greater cultural competency in gender-affirming care among healthcare providers (Dowshen et al., 2017). Another study was conducted by Wilson et al. (2013) in Alameda County, California with a small sample of African-American trans women living with HIV. In this study, the authors focused on delineating what their respondents identified as barriers to continued HIV treatment which were gender-related stigma, stigma from peers, and institutional distrust. They also identified a lack of provision of hormone therapy and other transition-related care as one of the reasons why they may not continue anti-retroviral therapy (ART) treatments, because they would prefer to access HIV and transition-related care at the same facility or from the same providers (Wilson et al., 2013). These findings were echoed in the Canadian Trans PULSE study, where trans women living with HIV and their service providers highlighted the need for integrated HIV services alongside gender-affirming care (Munro et al., 2017).

1.2. Challenging existing research strategies

Existing research underlines the barriers that research teams face in conducting research with transgender women living with and affected by HIV (e.g. Fontanari et al., 2019). Often, research on trans women and HIV is either squarely focused on health behavior (such as treatment-seeking or adherence to medication and condom use) and does not include the voices of trans women themselves, or if it includes trans women's experiences in their own words, is not focused on how services could be restructured to better accommodate trans women's specific needs. Even some of the most comprehensive literature reviews often feature recommendations made by researchers and authors who are not transgender women, rather than directly incorporating transgender women's voices into the analysis and discussion (Jaspal et al., 2018; Poteat et al., 2014; Reisner et al., 2016). Our initial approach to this study was to identify research priorities, but in the data collection process it became clear that our respondents' priorities were to first and foremost address the existing issues with health and social services available to them. Centering the contributions of our research respondents meant deemphasizing our original goal of furthering research in favor of following the lead of our participants. We offer this article as a model of how to adapt and be responsive to the process of data collection when doing community-based participatory research, especially when almost all of our research team is transgender, and a majority of us are transgender women.

The literature demonstrates that transgender-led research that centers and prioritizes the language of respondents themselves, and the particular issues that transgender women living with and affected by HIV face in accessing vital health and social services, remains underexplored. We sought to better understand how to enhance health and social services for trans women affected by HIV from their own point of view. Thus, our key research question became: How could the health and social services landscape be improved to better address the needs of transgender women living with and affected by HIV? Central to this exploration is our attempt to bring forth participants' own ideas, thoughts, and words about how to better health and social services that are meant to serve them. In adapting our research to follow the data, and in this case the priorities that our respondents articulated themselves, we also became aware of the insider-outsider nature of our work, which we will expand upon in the next section.

2. Methods

2.1. Study design and data collection

Recent scholarship from Rosenberg and Tilley (2020) has outlined a way to decrease the potential for research to reinforce inaccurate social stereotypes, while cultivating nuance and data depth. Rosenberg and Tilley outline what they call an "insider-outsider staircase" to measure the level of involvement that transgender researchers have with transgender-specific research. They stress that qualitative research on transgender populations and their experiences is best suited to insider-outsider led research as transgender scholars necessarily bring their own lived experiences and positionality as trans to bear on their work with trans populations. Towards this end, our original team was exclusively transgender-identified and only those team members who themselves were transgender women conducted the interviews and focus groups across all five provinces where data were collected. The current writing team features predominantly trans people; however, we recruited a cisgender scholar with particular expertise in qualitative data analysis and who could appreciate the strength of the project dataset. We sought out someone with relevant expertise in managing large, qualitative datasets and found a uniquely qualified cis-identified scholar with the requisite skills. This researcher was included in the analysis phase after data collection had been completed and the perspective this scholar offered proved to be invaluable in helping us to understand how the work could be interpreted, or even misinterpreted, by an audience without the lived experience of being transgender. Rosenberg and Tilley (2020) emphasize the importance of including "relative outsiders" who can provide alternative insights, and challenge assumptions that may be shared by "relative insiders". We have thus shifted from a transgender-only to a transgender-led team and have put

the insider-outsider principles that Rosenberg and Tilley outline into practice. The original team of seven trans-identified researchers and community leaders came together in 2014 to work on a project focused on transgender women and HIV. The initial objectives of the group were to: 1) engage in a community-based research priority setting process with trans women affected by HIV, 2) connect trans women, communities, and leaders in urban centers across Canada, and 3) identify key priorities for future research. Team members were based in Montreal, Toronto, London, and Halifax. After securing funding we met in person to establish a Terms of Reference and a detailed project plan, and to participate in training on qualitative research methods and research ethics.

Because the team wanted to reach a diverse sample of trans women across Canada, we extended data collection to include Winnipeg, Edmonton, and Vancouver. We focused our recruitment efforts on reaching trans women most impacted by HIV, including racialized and Indigenous women, women with experience as sex workers, and people who use drugs. Trans women on the research team traveled to each city to conduct focus groups and semi-structured interviews, in both English and French. Recruitment was facilitated via partnerships with local community organizations and the hiring of peer outreach workers who facilitated connections between researchers and participants, particularly in Winnipeg, Vancouver, and Edmonton where the team had a more limited social network. Community organizations were selected based on their reputation as sex worker- and trans-positive. Participants were provided with a $50 honorarium for participating in focus groups or interviews.

The design of recruitment and data collection materials was collaborative, though only transgender women from the research team conducted interviews and focus groups. Most focus groups were open-call, but in Winnipeg an Indigenous-only focus group was conducted in consultation with an Indigenous elder and researchers from Indigenous communities. Similarly, an African, Caribbean, and Black-identified (ACB) group was conducted in Toronto. In total, seven focus groups (with 47 participants) and 27 individual or paired interviews were carried out in: Edmonton (seven interviews); Toronto (seven interviews and two focus groups); Vancouver (five interviews and one focus group); Montreal (four interviews in French, two interviews in English, and two focus groups, one in each language); and Winnipeg (two interviews and two focus groups).

Every participant was given detailed information about the goals of the study and each provided both verbal and written consent to participate. The Office of Research Ethics at the University of Waterloo and the Non-Clinical Trials Health Research Ethics Board of Newfoundland and Labrador provided ethics approval. Participants were asked to name services that trans women in their area access, about the sources of help they themselves reach for in times of crisis, and about services they would like to create for trans women affected by HIV if given the option and resources. Interviews and focus groups were audio-recorded and then transcribed.

2.2. Data analysis

Three team members, two of whom are trans-identified, of which one is a trans woman, but were not engaged in the original data collection, led the data analysis. All transcripts were coded and organized using Dedoose (8.1.8), a qualitative analysis software. Data analysis was informed by the steps suggested by Saldañia (2012). The analysis took place in three phases: initial coding, axial coding, and theory generation. This process started with open coding, reviewing the transcripts manually and pulling out phrases and sections for discussion that team members found striking. At this early stage all three team members engaged with analysis reviewed the same transcripts. The data analysis team made a conscious effort to remain open-minded, close to the data and to participants' voices, and let the process of analysis develop organically. This team met on a weekly basis to talk through their observations and after several weeks moved onto developing initial codes based on these observations. Next, the transcripts were divided such that focus groups transcripts were coded by at least two people to promote intercoder reliability. Two team members would code the same transcript to then review it together with the third team member. Once consensus was reached, the team moved to the next transcript. Consensus was key because the analysis team included our cisgender-identified scholar and thus a true consensus indicated an agreement not only about an identified theme, or that a particular piece of a transcript should be coded the way it was, but also that it would resonate and make sense to both relative insiders and relative outsiders to trans women's communities. Initially, the coding team identified two key themes among respondents: an appraisal of the gaps and limitations of the existing health and social services landscape, and the ways in which respondents imagined the service landscape otherwise.

As this process unfolded, more codes and subcodes were added to capture the nuances reflected in what was shared by participants within focus groups and interviews alike. Coding continued alongside weekly meetings, where codes were reviewed and the analysis discussed. During this process, the team decided to focus more specifically on how respondents imagined the health and social services landscape could change to be more responsive to their needs as transgender women living with and affected by HIV. We therefore further bifurcated that set of codes into structures of services versus types of services. When nearly all the transcripts had been coded, the team began a process of axial coding (Saldañia, 2012). Codes and the quotes they comprised, at this stage, were closely examined. Codes that were similar in meaning were merged, aiming to connect several codes into themes with the goal of theory generation. Within this recategorization, types of services emerged less frequently than structures of services. Thus, the decision was made to prioritize a rich analysis of how respondents reimagined the structure of health and social services. Once codes were finalized, the team revisited the data and filtered through coded excerpts based on the identified priorities and theories from the analysis. This final phase resulted in the key themes featured in the results section of this article: trans-friendly and trans-specific services, integrated health services and aid in navigating complex systems, and comprehensive community-based services.

3. Results

3.1. Sample demographics

Our team recruited 76 trans women living with and/or affected by HIV across five urban centers within Canada. The groups were ethnically diverse including 38% Indigenous women, 26% white, 18% Latinx, 12% African, Caribbean, or Black, and 4% South Asian or Southeast Asian. Participants ranged in age from 18 to 65, with an average age of 40 (SD 10.5). Among our participants, 20% reported living with HIV, 63% were HIV-negative, 7% had never tested, 3% had not returned for their results, and 4% did not want to disclose their status. Of the women who reported living with HIV, 47% were Indigenous, 40% Latinx, and 20% were white. In relation to Hepatitis C, 22% were positive, 75% were negative, and 3% had no response. Lastly, 78% of our sample had experience with or a history of sex work (see Table 1).

3.2. Themes from the data

The results presented center the ways in which trans women who participated in this project reimagined health and social services. Key themes that emerged in these discussions highlighted the need for 1) trans-friendly and trans-specific services; 2) integrated health services and aid in navigating complex systems, and; 3) comprehensive, community-based services. The quotation that features in the title of this article foreshadows our analysis of the results. The original goal of this study was to produce a set of concrete research priorities identified by

Table 1
Sample demographics ($n = 76$).

Age	Number of Participants	Percentage of Participants
18-24	5	6.8
25-34	18	24.3
35-44	24	32.4
45-54	22	29.7
55-64	4	5.4
65+	1	1.4
No answer	2	2.8
Mean Age (Standard Deviation)	39.95 (10.54)[b]	
Range	18–65	
Language of Interview/Focus Group		
French	13	17.1
English	63	82.9
Ethnicity[a]		
Aboriginal or Indigenous (e.g. Mohawk, Cree, Inuit, Métis)	29	38.2
African, Caribbean, or Black (Black African, Black Canadian, Black Caribbean, Black Latin American)	9	11.8
East Asian (e.g. Chinese, Japanese, Korean, Taiwanese)	1	1.3
Latin American (e.g. Argentinian, Mexican, Nicaraguan)	15	19.7
Middle Eastern or North Africa	2	2.6
South Asian or South East Asian/ Canadian	3	3.9
White Canadian/White American/White European	20	26.3
Other	3	3.9
HIV ("What was the result of your last HIV test?")		
Positive	15	19.7
Negative	48	63.2
Don't want to say	3	3.9
Didn't go back	2	2.6
Never tested	5	6.6
No response	3	3.9
HepC ("Has a doctor ever told you that you have Hepatitis C?")		
Yes	17	22.4
No	57	75.0
No Response	2	2.6
Sex Work ("Have you exchanged sex for money or other goods?")		
Yes	59	77.6
No	14	18.4
No Response	3	4.0

[a] Check all that apply; frequencies may sum to more than 100%.
[b] The age data only includes 73 respondents because 3 had to be censored for incomplete responses.

transgender women living with and affected by HIV. However, many respondents were less concerned about research than our research team, and as one respondent stated "I'm not interested in research; I'm interested in services". We therefore shifted focus to detail the concrete ways in which transgender women respondents suggested existing health and social services could be improved to better address their needs.

3.3. *Trans-friendly and trans-specific services*

The need for more trans-friendly, as well as more trans-specific services, was identified by respondents in nearly every interview and focus group. For our purposes, trans-specific services means health and social services that are intended to be delivered primarily if not exclusively to trans people. Trans-friendly means that services may not designate trans people as their primary target population, however, staff are well-trained and capable of providing services to transgender people in a culturally competent, gender-affirming way. To begin to illustrate this distinction, one interviewee from Vancouver said "in the trans community … we've heard 'no' so many times that we stop asking doctors, health care providers, service providers, am I safe here, are you going to support me?" She went on to say that "if trans people aren't specifically mentioned, often we assume that we're excluded. So, you know, health care providers need to do a better job of saying that they do work with trans folks." What this respondent points to is that often, trans women access services across various settings in which it is unclear whether they will be welcomed and affirmed for who they are, or even given adequate care. Even in instances where their clinical or other needs may not be different from their cisgender counterparts, (e.g. a blood draw for HIV testing is the same for everyone), it was often unclear if they would find a welcoming and trans-friendly environment. This same interviewee went on to say "I'm not a huge supporter, you know, of policies that segregate groups, but I do think where our movement is at, trans-specific services are necessary until they're not necessary anymore." This interviewee thus points to the need for trans-specific services as a necessary stop gap because not all services are adequately trans-friendly. For her, trans-specific may be a temporary intervention on the road toward making all health and social services more trans-friendly and culturally competent.

The idea of trans-specific services came up in focus groups as well. In the Indigenous-only focus group, participants consistently referenced an Indigenous community center that housed multiple programs that many of them had used before. While they each had varying experiences in accessing this Indigenous-specific facility, they all agreed that it served as an excellent model for demographic-specific services. Specifically, they spoke about the compounding issues they faced in accessing health services as Indigenous trans women living with and affected by HIV. When asked to envision a program that would meet their communities' needs and desires, they said something akin to this Indigenous-centered facility was ideal. The interviewer asked, "would you want a place where you could see someone about hormones and about HIV and addictions all in one?" and multiple participants responded at once in excitement and agreement. One summarized by saying "addictions, treatment, and general health, yeah" and another added "all in one building." In this instance, trans-specific also means that not only would staff be well-trained on culturally competent and gender-affirming approaches, but also that they would be knowledgeable on the specifics of transition-related healthcare. Thus, while some types of services where the needs of trans women are not clinically or biomedically different from those of other populations could be made trans-friendly by cultural competency training for staff and gender-affirming procedures and policies, there remain contexts in which trans-specific services would still be necessary. Trans specific services are especially relevant in relation to how hormones and gender transition-related needs interact with other healthcare needs such as HIV and addictions or substance use treatment.

In a Montreal focus group, respondents echoed these concerns related to specific versus friendly services. Several participants in this group had gender-affirmation surgery, or 'bottom surgery' as they referred to it, and they noted how being 'post-op' changed the way they accessed services. Participants referenced several women-only programs and facilities and their oftentimes unclear policies on trans-inclusion (or exclusion). Because of this lack of a clear stance at one homeless shelter that a respondent had stayed at, she said "if I could find a friend that could take me in for about a month, I would prefer that than stay in these shelters." She explained that "especially after the last shelter I was in when I found out they only took me just because I was post-op." She ended by stating "they wouldn't take pre-op trans women, and a lot of them are like that." This specific phenomenon in women's only spaces that respondents named points to the utility of both trans-friendly and trans-specific services. Even this respondent who met the shelter's criteria for admittance said that she would rather make alternative arrangements than to use those services again because of that policy.

One of the primary motivations for wanting both trans-friendly and trans-specific services was safety. In fact, a respondent in Edmonton said, "over the years I mean I've had workers say, 'go stay at the [redacted]'; it's a shelter downtown … over the years it's been like, no I would get killed over there, it's a matter of safety." This type of response

to existing services and facilities that lack trans-friendly policies, or that have unclear policies, was common among participants from all locations where data were collected. Some respondents genuinely feared for their lives. 'I would get killed over there' is not a figure of speech for just being afraid of being harmed generally. In Edmonton and other urban centers where a plurality or majority of participants were Indigenous, many respondents named specific experiences and even specific locations within their cities where they experienced previous or ongoing violence.

The fear of physical violence was compounded by perceived fears of navigating the city as a whole. Later in the same interview as above, this participant pointed to the service worker's lack of lived experience that led to a lack of genuine concern when she expressed trepidation about accessing that shelter the worker recommended. That trepidation may have been what led her to then add "they don't get that. Like certain places we just can't be, right?" This can be read in two ways. First, 'we just can't be' could simply mean we, meaning trans women living with and affected by HIV, cannot go there, or we cannot access that service. But it also could mean we cannot be ourselves there.

The gravity of this need for both trans-specific and trans-friendly services was made apparent in another Vancouver interview. Here the respondent spoke to how a lack of knowledge around which resources will be available to transgender women living with and affected by HIV leads to isolation. And in the case of people with terminal illnesses or who are aging, "they're not accessing resources because they don't know, or they just don't have the energy." This sentiment was also common. Consistently being denied services or feeling less than welcome when accessing them becomes burdensome and makes marginalized people, like transgender women, less likely to keep trying to get the services they need. This respondent who pointed to the lack of knowledge about services or the energy to seek them out also named hospice as a particular priority need for trans women living with and affected by HIV. When asked why, she said simply "because too many people are dying alone."

3.4. Integrated health services and aid in navigating complex systems

Issues in the above section largely refer to micro-scale or individual-level interactions in accessing services. Respondents pointed to the need for trans-friendly, and at times trans-specific services, often while narrating their own experiences as evidence. However, their suggested improvements to existing health and social services were not limited to making services more trans-friendly or ensuring that individual providers are well-trained to serve trans women respectfully. In addition to the issues related to trans-friendly and trans-specific, respondents made structural critiques about the limitations of the landscape for services and concrete suggestions for improving accessibility which they suggest would necessarily improve retention. A common scenario that was outlined involved having to attend one clinic for sexual health services and gtesting, another for hormone replacement therapy if a given respondent took hormones, another facility or service to be linked to a case worker who could help with securing housing or disability coverage or employment opportunities, and still another facility for mental health services like counseling, therapy, and even peer support groups. Respondents consistently expressed frustration with the state of affairs in which services are siloed from one another. Two types of solutions to the issues were proposed. One is to combine services into single facilities that can address the myriad needs of trans women living with and affected by HIV. The other is to create structural supports, and often case-worker style positions, that would aid them in navigating complex systems of health and social services.

When asked about their preference for having multiple doctors where one "did stuff for trans health and one that did stuff for HIV, [or] would you prefer to have one doctor that did both?", Montreal focus group participants were unanimous about their preference to have "one doctor for everything", saying that "one is more than enough" and that going to different doctors is "just too much". Vancouver focus group participants also cited the need for doctors with cross-training in both trans-specific medical care and HIV treatment, but they also added other services to their model of a trans center. Specifically, one Vancouver focus group participant summarized the ideal scenario which involved not only "developing trans awareness and HIV awareness," but also "self-defense courses, a shelter, a soup kitchen, free education, home support, hospice, counseling, and life skills training".

Toronto-based African, Caribbean, and Black-identified (ACB) focus group participants also stressed the need for physicians and other healthcare providers who are cross-trained on HIV care and working with trans people. ACB focus group respondents in particular stressed the need to educate health providers on the intersection of HIV and gender transition as part of addressing the health needs of trans women living with and affected by HIV. A participant synthesizing multiple respondents' suggestions articulated the need for "prevention and treatments for trans people designed by trans people, so it's not a cis-gendered perspective, but a trans person's reality." She went on to suggest that integrated health services should also include "transition supports" for HIV-positive trans women so that through seeking out and patronizing services, they understand "the impact on being positive and transitioning with hormones and taking care of yourself in terms of long-term care." This necessarily means that the healthcare providers themselves would need to be educated on this intersection of HIV and gender transition.

The Winnipeg Indigenous focus group participants emphasized the need for cultural competence in working with Indigenous people. They cited frequent issues in advocating for themselves as both Indigenous and transgender, in addition to living with or being affected by HIV. For this group, sex work was often cited as another life experience that compounded stigma faced in accessing services. When one participant pointed to an existing program that "has a liaison worker for social services" she said, "that's the type of thing that we need cause … the worker works with sex workers and sex trade workers, so we need that type of liaison for the trans women, especially who are Indigenous." The need for a liaison was underlined by other participants in the focus group as well. One shared that "to try to navigate to talk to [social service workers] … they're just not responsive to me" and "they just refuse to deal with me." She went on to reiterate that for her, "it would be, again, social services that somebody could navigate that for us."

3.5. Comprehensive community-based services

The accessibility and safety of services, as well as currently unmet social and cultural needs, were further addressed in many of the focus groups and interviews through proposals for comprehensive community-based services. Similar to the idea of integrating health services so that they could be accessed in one place, participants reflected a need and desire for community centers to be developed to offer centralized services that support social connectivity and holistic wellness. The details of such integrated services varied by individuals and focus groups, but many spoke to the need to integrate services connected to housing, food security, education and training, and mental health. One participant from Edmonton imagined a "multiplex" where the facility would offer permanent housing in one part of the building, while also offering supports to help women get jobs, provide sexual health resources, receive counseling support services, "and then there could be other services, it could be short little bits of types of schooling or whatever that's free that they can access whether it be anything from make-up to fashion design to just basic high school diploma stuff …"

Housing was frequently an issue addressed within these community centers, as study participants across Canada highlighted the scarcity of housing solutions for their communities. As such, many women incorporated either permanent housing, and or shelter services, into their descriptions of the comprehensive community-based services they would like to see. One participant from Edmonton described: "a social

area, a place to have, offices for privacy and like some of the trans are homeless so there's an area where they can clean up and do laundry maybe and shower and be able to get a gift card for Safeway and hygiene products." Food security was also addressed in multiple participants' visions, often through a food bank, as well as the provision of free meals and snacks. Per a Toronto interviewee: "hot meals, and not just a meal with like, that you could feed a child. A hot meal. Mashed potatoes. Roast beef. Something real."

Accessibility was addressed by multiple women through proposals of low-barrier shelters and community spaces where there are few requirements, if any, for accessing services. One woman from Toronto stressed the importance of providing the services without asking questions or imposing limitations, stating that "I will create a place that they can go to sleep, medication, education, any time they want." Looking at people holistically and minimizing the pathologization of their experiences was also often discussed as part of improving ease of access to services. Another woman from Toronto stated: "That's always been a dream of mine, having money and being able to provide a safe house where people could come in and be themselves and you know, be treated in a way with respect and dignity rather than being treated as a person with a disease."

Multiple participants also described the need for more informal spaces within community services, reflecting that such spaces engender less stigma and increased comfort. A desire to access psychological support in more relaxed environments was reflected by numerous women, some of whom described drop-in centers with couches and food. One woman from Vancouver described a situation where counseling could be embedded and easily accessed: "I would create like a centre, a drop-in centre type deal, where we had rooms if somebody needed a place to just be with sisters. They have that option, with counsellors or just us, just girls." A participant from Edmonton, in describing the community center she envisioned, talked about the importance of having space to simply be around other trans women: "I think that's where there's value. Sharing stories, talking about safety, you know. I find the more things are just integrated into daily life better I suppose."

Similar to the expressed need for culturally competent health services, some participants spoke to the importance of integrating cultural support in these community-based services as well. Multiple participants referred to the greater ease they feel when they are able to be in spaces where others from their cultural communities are present. Participants also described how having access to cultural and spiritual activities within a context intended to also serve trans women would serve them better and more holistically. One participant interviewed, in discussing having activities specifically oriented to Indigenous women, stated "… Because it is a healing – it's almost like ceremony, right? And they need ceremony to feel like more positive instead of negative." Another participant from the focus group in Toronto reflected on her desire as an Indigenous woman to see spaces that support the spirituality of trans women as well: "It's the spirit you've got to feed first and then you can work on everything else".

3.6. Limitations

Our study was conducted in five urban environments across Canada, and the geographic specificity of these larger cities, and their respective health and social services landscapes, limits generalizability. Other researchers have begun addressing similar issues of holistic approaches to HIV care for trans people in less metropolitan or urban areas (Perez-Brumer et al., 2018). Additionally, new research with trans communities has more explicitly framed settler colonialism as a social and structural determinant of health for Indigenous communities (Martinez-Velez et al., 2019). The specificity of Indigenous experiences, and of rural trans communities, merits further attention and future research. Additionally, differences across provinces were not highlighted in this article; however, they were noted in the process of analyzing and coding the data. Lastly, a majority of our respondents had some history of sex work, a commonality we noted, but did not have the space to fully explore. Future work could and should take up these questions of Indigenous communities' needs, geographic differences, and how trans-friendly service provision would also entail a non-stigmatizing approach to sex work more explicitly. For this article, we chose to focus only on those themes and indeed concrete recommendations that were present in all five urban centers in which research was conducted.

4. Discussion

Building on the results above, we present five key points that we hope readers will take with them to their own research and service provision. First, the design and delivery of services needs to be responsive to transgender women living with and affected by HIV. As discussed above, rigid gender-segregation policies, strict service eligibility requirements, and a lack of comprehensive training on how to work with transgender communities create and exacerbate barriers for transgender women in accessing existing services. Our data on the perspectives of transgender women living with and affected by HIV indicate that clarifying existing policies vis-à-vis gender inclusion and providing training opportunities to program staff would help to address these barriers at the level of service provision. Even after an intervention or service has been designed, funded, and implemented, the means of delivery and the training that personnel receive can still be changed to adapt to the target community's needs. Since service delivery is a later stage of program implementation, it is often targeted for reform. However, much earlier stage reforms are needed to truly incorporate the perspectives offered here via the participants in our study.

Responsive program design is key to improving health and social services for transgender women living with and affected by HIV. From our participants' perspectives, employing transgender people, especially trans women who are living with HIV, who are also Indigenous or First Nations, or have a history of sex work, to deliver services would make trans women more likely to patronize programs. Moreover, trans-specific services are paramount in ensuring that trans women feel safer. While not all services can or should be designed as trans-specific, striving to design trans-friendly programming can better serve trans communities who may otherwise not access services. We would also discourage conflating trans-inclusive with trans-friendly because the former tends to rely solely on design, or inclusion by name. The latter, however, is a result of actions taken to be responsive to feedback from trans community members and our data indicate that trans-inclusive does not always signify trans-friendly to patrons. Both design and delivery of services must be responsive to trans women living with and affected by HIV to be successful and reach program goals.

Third, it is important to recognize and honor the expertise that comes from lived experience. While researchers often spend years learning methods of analysis, data collection, scientific writing, and other vital skills for the process of communicating results of research, actually living through the precarious conditions in which trans women, especially those living with HIV, often find themselves must be treated with the same level of respect. The authors encourage readers to consider the value of their own respondents' words and to recognize the important process of translation in which they as researchers are engaged. That process entails translating important knowledge generated through lived experience into the scientific literature in the hopes of enacting change. As Rosenberg and Tilley (2020) argued, that translation process is best led by those who have both the lived experience of being transgender and the disciplinary and scientific expertise to make the inherent meaning in the data matter. We have offered this article as a model for how to think about this insider-outsider relationship and how it can affect data collection with transgender researchers and participants in other thematic areas and geographic contexts. Therefore, we urge researchers to accurately represent the perspectives of their respondents. One way to hold oneself accountable to those perspectives is to make a point to publish the words as they were spoken within their manuscripts.

Interpretation also matters, of course. However, it is vital that trans women be allowed to speak for themselves, especially in the pages of academic journals in which they are often spoken about, but rarely spoken to.

Related to the previous point, we wish to emphasize the value of community-based participatory research in doing work with marginalized, or otherwise 'hard to reach' populations, such as trans women living with and affected by HIV. Gelaude et al. (2013) reviewed programs that targeted young trans people of color and gleaned that the most successful were those that were intentionally designed in collaboration with trans people. Logie et al. (2019) also offer a model for a trans-led, qualitative study designed to address compounding stigmas of racialization, HIV, and transgender status in Toronto, Canada. While this research was conducted across Canada, the process and the ethos are entirely reproducible in other contexts. Conducting similar research to evaluate the health and social services landscape for transgender women living with and affected by HIV in other geographic contexts is paramount. Our specific results may not be generalizable given the specificity of the Canadian systems, including the relatively robust government funding available compared to low- and middle-income countries, but our transgender-led, community-based participatory research design and the insider-outsider lens we adopt in our analysis are.

Lastly, we invite readers to reflect on the common notion that transgender women, especially those living with HIV, are considered 'hard to reach' or 'hidden' populations (Flanagan and Hancock, 2010). The phrasing itself implies a unidirectional conception of transgender women's communities in which researchers, service providers, clinicians, and outreach workers must seek out trans women to recruit into services. In reality, our participants, and much of the authors' experience, suggest that perhaps the reverse is true. Trans women living with and affected by HIV strive to find trans-friendly and culturally competent services, but struggle with identifying which programs are truly responsive to their needs. Additionally, research participants bemoaned the necessity of *juggling multiple referrals,* that is, having to attend different clinics or programs to meet different needs such as HIV care, transition-related care, STI screening, and so on. In fact, our results demonstrate that trans women are often adept at navigating complex, overlapping systems, and rely on word of mouth and community familiarity with programming to access vital health and social services. And indeed, recent work by Restar et al. (2019) identified this specific issue and proposed a framework for a gender-affirming approach to HIV care. Despite all the efforts made by trans women seeking services, many trans women's needs go unmet. 'Hard to reach' seems to imply that trans women make no effort to meet their own needs, when in fact it is the services that may be 'hard to access' (Guta et al., 2014; Riggs et al., 2014). Further, this language suggests that researchers are not already embedded in trans women's communities. Trans women, and trans people broadly, are also researchers, service providers, clinicians, and outreach workers. The pockets of trans communities that may seem hard to reach to cisgender people are often already a part of transgender researchers' extended social networks.

Author credit statement

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Appendix A. Supplementary data

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